



The Update

2009 Volume IV

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Join us for an exciting evening featuring The Rusty Griswolds band! We are thrilled to have been accepted as a beneficiary of such a fun and generous community event. Tickets are \$50.00 each, and \$30.00 of that will come right to the Epilepsy Foundation for everyone who selects us as their preferred beneficiary (which also qualifies as a \$30.00 tax deductible charitable contribution for you!) The event committee has a great evening planned which will include a Silent Auction, a Basket Raffle and great music!

Go to: www.therustyball.com to get all the information and purchase your tickets. Remember to select the Epilepsy Foundation as your preferred beneficiary!



Gather your friends—we hope to see you all on November 21st!



Mason Mini Marathon

November is Epilepsy Awareness Month and on Sunday, November 8, 2009, we will gather in Mason for the 2nd Annual Mason Mini Marathon. This 15K run and 5K run/walk will start and end at Mason High School in beautiful Warren County. For more information and to register, go to:

<http://www.cincinnati-epilepsy.org/mason-mini-marathon.php>.

All proceeds from this race will benefit the programs and services of the Epilepsy Foundation of Greater Cincinnati.



Kathy Stewart

Well, it is November, which means it is Epilepsy Awareness Month. There are so many issues that surround epilepsy that this is the perfect time to "Talk About It". One event that our National Office and affiliates from around the country are promoting is called "Talk About It". This is where people host a gathering in their home, favorite restaurant or entertainment facility and they spend part of the evening talking about epilepsy—the best ways to beat the stigma and uncertainties of epilepsy, what it is, how it can affect you and to work to dispel any myths that are associated with epilepsy. Sometimes when people have gatherings at their home, especially during the holiday season, guests are asked to bring an item. Some hosts have asked that instead of an item, a donation to the Epilepsy Foundation of Greater Cincinnati would be appreciated. So, we encourage everyone to celebrate epilepsy awareness month and help us TALK ABOUT IT!

Kathy Stewart, Executive Director

Reaching out to Unserved Areas



Although our name states that we are the Epilepsy Foundation of Greater Cincinnati, our service area spreads far beyond the borders of Cincinnati. We are often on the roads in Indiana, Northern Kentucky and eastern Ohio providing needed in-services and support. Recently one of our campers, who lives in Huntington, West Virginia, contacted our

agency about providing services in his school and community. Always ready for a challenge and determined to dispel the myths surrounding epilepsy and to empower people, we are meeting with concerned individuals in the community to come up with a game plan to bring support services and epilepsy awareness to the Huntington area.

If you live in a rural area and are in need of epilepsy services, please call our office at 1-877-804-2241 and speak with one of our dedicated staff. Together we are making a difference!



Ask the Expert: What is Lennox-Gastaut syndrome?

David M. Ficker, MD
Director, Epilepsy Monitoring Unit, Cincinnati Epilepsy Center
University of Cincinnati Medical Center



David M. Ficker, MD

Lennox-Gastaut syndrome (also called LGS) is an epilepsy syndrome that was first described in the 1930s based on certain EEG patterns. The syndrome was officially recognized by the International League Against Epilepsy in 1989. The syndrome represents only about 5% of all epilepsy syndromes. LGS is characterized by three major clinical features:

1. Presence of multiple seizure types (tonic, atonic, generalized tonic clonic or atypical absence)
2. Presence of a characteristic EEG pattern (generalized slow spike and wave)
3. Presence of mental retardation

and developmental delay. LGS typically begins around the ages of 3 and 5 and usually persists into adulthood. Seizures are very difficult to control and seizure freedom is rare. The most disabling seizure type in LGS is a "drop seizure." A drop seizure consists of a sudden increase in muscle tone followed by a fall (tonic seizure) or a sudden loss of muscle tone with a fall (atonic seizure). It is often difficult to differentiate a tonic from an atonic seizure, so the term "drop seizure" is often used. Because of the fall that may result from drop seizure, injury is very common. Individuals with LGS may need to wear a helmet to prevent head injury.

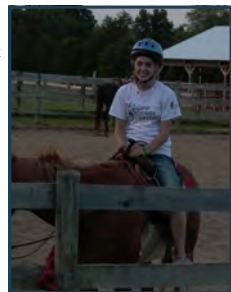
Treatment generally consists of a select group of seizure medications. Some of the currently available medications have been specifically studied in LGS. Some other seizure medications potentially can worsen seizures in LGS. In rare circumstances, some individuals might benefit from brain surgery called corpus callosotomy which may reduce the number of drop seizures. Sometimes the vagus nerve stimulator or the ketogenic diet may be used. The Epilepsy Foundation has launched a new online resource www.LGSandMyChild.org tailored to parents of children with Lennox-Gastaut syndrome (LGS).

Camp Dream Catcher Serves Record Number of Kids!



Each year the number of children served by Camp Dream Catcher continues to increase and 2009 was no exception! Between our weekend and summer camps, over 130 kids enjoyed time together in the outdoors, made friends and learned that they are not alone in their struggles with seizures.

Because of the support of many, we were able to welcome all kids to camp, even if they could not afford the cost of camp. This was made possible by grants from Ortho-McNeil,



Parents Against Childhood Epilepsy and a number of individual donors. One couple from northern Ohio whose granddaughter with epilepsy was too young for camp provided a much needed scholarship for another child. Other people provided scholarships in memory of a loved one with epilepsy or friend diagnosed with the disorder. If you would like to support a child at camp please send in your donation, we will be sure it impacts the life of a child in a special way.



Calendar of Events

November 8, 2009; 9:00 AM

Mason Mini Marathon; Mason High School

November 10, 2009; 6:00-7:30 PM

Clermont County Epilepsy Support Group:
Miami Township Civic Center Conference
Room (6101 Meijer Dr., Miami Township, OH
45150)

November 11, 2009; 5:30-7:00 PM

Warren County Epilepsy Support Group: Kidd
Coffee (322 Reading Rd., Mason, OH 45040)

November 18, 2009; 6:00-7:30 PM

Northern Kentucky Epilepsy Support Group:
St. Luke Hospital West, Lower Level
Conference Room (7380 Turfway Rd.,
Florence, KY 41042)

November 19, 2009; 9:00 AM

Seminar "Minding Your Health": The Health
Foundation of Greater Cincinnati

November 19, 2009; 6:00-7:30 PM

Hamilton County Epilepsy Support Group:
Epilepsy Foundation's Main Office (895 Central
Ave., Suite 550, Cincinnati, OH 45202)

November 19, 2009; 6:00-7:30 PM

Butler County Epilepsy Support Group: Janet
Clemmons Center (282 N. Fair Ave., Hamilton,
OH 45011)***Note Date Change***

****** December 2009 ******

No support groups

December 3, 2009; 9:00 AM

Seminar "Update on New Treatments and
Devices for Epilepsy": The Health Foundation
of Greater Cincinnati

January 12, 2010; 6:00-7:30 PM

Clermont County Epilepsy Support Group

January 13, 2010; 5:30-7:00 PM

Warren County Epilepsy Support Group

January 20, 2010; 6:00-7:30 PM

Northern Kentucky Epilepsy Support Group

January 21, 2010; 6:00-7:30 PM

Hamilton County Epilepsy Support Group

January 28, 2010; 9:00 AM

Seminar (topic TBA): The Health Foundation

of Greater Cincinnati

January 28, 2010; 6:00-7:30 PM

Butler County Epilepsy Support Group

February 9, 2010; 6:00-7:30 PM

Clermont County Epilepsy Support Group

February 10, 2010; 5:30-7:00 PM

Warren County Epilepsy Support Group

February 16, 2010

Mardi Gras Gala—More information to come!

February 17, 2010; 6:00-7:30 PM

Northern Kentucky Epilepsy Support Group

February 18, 2010; 6:00-7:30 PM

Hamilton County Epilepsy Support Group

February 25, 2010; 9:00 AM

Seminar (topic TBA): The Health Foundation
of Greater Cincinnati

February 25, 2010; 6:00-7:30 PM

Butler County Epilepsy Support Group



Advocacy Matters

The Americans with Disabilities Amendments Act of 2008 (ADAAA) was enacted on September 25, 2008, and became effective on January 1, 2009. This law made a number of significant changes to the definition of "disability." Congress directed the US Equal Employment Opportunity Commission (EEOC) to amend its ADA regulation to reflect the changes made by the ADAAA, published in the Federal Register September 23, 2009. Questions and answers to common questions surrounding the ADAAA and how it can effect you can be found at <http://www.cincinnatiepilepsy.org/advocacy.php>.

Get Connected, Stay Connected!



With 119 groups and over 7000 members, eCommunities has something for everyone. Whether you are a teen, adult, parent, senior or caregiver there is a place for you here. Look for the latest on treatments, advocacy, employment, education and other experiences people like you are going through. It's a great place to go for the support you need.

Go to <http://epilepsyfoundation.ning.com/> to chat or just visit.

Become a fan of the Epilepsy Foundation on Facebook.com. Get up to date information of the happenings and events surrounding epilepsy in Greater Cincinnati.



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We're on the web!
www.cincinnati-epilepsy.org



Find a lawn service
in the same city as your lawn.

When you need something local, why search anywhere else? The Cincinnati Bell Directory and cbyp.com have it all.

Real local. Real fast.
Cincinnati Bell Directory
The Real Yellow Pages™



Inspired by his son who has epilepsy, TV's star of *Heroes*, Greg Grunberg is encouraging the nation to take epilepsy to the streets and just talk about it. Greg recently set up a great website at www.talkaboutit.org where he and other stars from Hollywood encourage people to bring awareness to epilepsy. Locally, we are doing just that as the month of November approaches, which is typically known as Epilepsy Awareness Month.

Kathy Stewart, our Executive Director is encouraging all friends of the agency to host a dinner party, get together with friends, or other social event and take a little time during the event to talk about epilepsy and also ask friends to support the agency financially. These gatherings can have a profound impact on the epilepsy movement and help support the work we do locally.

One family in Maineville is stepping up to the plate in accepting this challenge to "Talk About It". The Legaults are turning their son's recent diagnosis of epilepsy into an extremely positive experience. Xavier, who has epilepsy, has spoken to the kids at his school about epilepsy and stands tall in proclaiming, "I have epilepsy, but epilepsy does not have me!" He continues to play football, soccer and to wrestle. Recently, the Legaults invited family and friends to join them at Lazer Tag to raise money for the Foundation. After an evening of fun, many people came away with more information about epilepsy and thanks in part to a visit from Channel 9 News, the evening raised \$400.00! On October 28, the Legaults will again be talking about it and raising money for the Foundation at The Blind Moose restaurant in Maineville. Thanks Legaults for your hard work and dedication.

Please join us as we host parties, play Laser Tag and much more to advance the cause of epilepsy awareness. The upcoming holidays give us a perfect opportunity to "talk about it" as we gather with family and friends. Don't be shy! Stand up with Xavier and let people know that we may have epilepsy, but epilepsy doesn't have us.

Looking for that perfect holiday gift? We still have 2010 Entertainment Books for the Greater Cincinnati area available for \$20.00 (\$25.00 with shipping). The books have lots of great deals and the sales benefit the Epilepsy Foundation of Greater Cincinnati!

You can visit www.entertainment.com to preview the book. They will be on sale through 12/10/2009.



The Update is a quarterly newsletter published by the Epilepsy Foundation of Greater Cincinnati

The Epilepsy Foundation of Greater Cincinnati is a United Way Agency founded in 1953 to assist people with epilepsy and their families in meeting their multiple health and social needs.

Executive Director:

Kathy Stewart

President of the Board of Directors:

James Comodeca

Mission statement:

The Epilepsy Foundation of Greater Cincinnati will ensure that people with seizures are able to participate in all life experiences; and will prevent, control and cure epilepsy through services, education, advocacy and research.